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PERSPECTIVES OF PATIENTS AND CAREGIVERS ON THE LOGISTICAL BARRIERS TO PROVIDING MENTAL HEALTH SERVICES IN UGANDA

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Mental disorders contribute substantially to the global burden of disease. Although mental disorders can be treated effectively, logistical barriers constrain the provision of evidence-based treatment in low- and middle-income countries. However, little is known about these barriers to treatment of patients in Uganda. We interviewed patients and care providers about their views on logistical barriers to the provision of mental health services. Results indicate that inadequate staffing, irregular medical supplies and the use of inferior medication constrained the delivery and utilisation of mental health services. Implications of these barriers include burnout among care providers and non-adherence to medical treatment among patients.

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INTRODUCTION

It is estimated that mental and behavioural disorders contribute as much as 7.4% of disability-adjusted years to the global burden of disease (Murray, Vos, Lozano, Naghavi, Flaxman, Michaud & Lopez, 2012). Disability-adjusted years are an absolute measure of health lost; many years of health life may be lost due to death and non-fatal illness or impairments (Murray *et al*., 2012: 2199). Five different types of mental disorders were associated with more than 15 million disability-adjusted years for each type by the year 2010. These were major depressive disorder (2.5%), anxiety disorders (1.1%), drug use disorders (0.8%), alcohol use disorders (0.7%) and schizophrenia (0.6%) (Murray *et al*., 2012). Major depressive disorder in particular also rose from 15th in 1990 to 11th in 2010 in the overall ranking for the 25 leading causes, representing a 37% increase in its relative contribution to the global burden of disease. The absolute share of burden attributable to mental and behavioural disorders is likely to increase in the future (Desjarlais, Eisenberg, Good & Kleinman, 1995; Murray *et al*., 2012; Patel, 2007). Low- and middle-income countries are likely to experience a higher burden of mental disorders than high-income countries for a number of reasons, including a projected increase in the number of young people entering the age of risk for the onset of certain mental disorders, conflicts, disasters, rapid urbanisation and macro-economic changes (Desjarlais *et al*., 1995). Urbanisation, for example, is a risk factor for mental disorders as it is associated with overcrowding, increased homelessness, urban poverty, disruption in family ties and loss of social support (Desjarlais *et al*., 1995).

Despite the high global burden of mental disorders, a wide mental health treatment gap still exists in many countries, especially in low- and middle-income countries where information on service utilisation is also less available than in high-income countries (Kohn, Saxena, Levav & Saraceno, 2004). A treatment gap refers to the disparity between the number of persons requiring treatment and the availability of treatment, largely as a result of scarce resources (World Health Organisation [WHO], 2008). Although persons with disabilities can live healthy and productive lives, they often do not receive appropriate health care because of a variety of structural barriers, including the limited number of health professionals providing care and services to the affected individuals (Stein, Stein, Weiss & Lang, 2009). Such a state of affairs is contrary to principles enshrined in the United Nations Convention on the rights of persons with disabilities, which came into force on 3 May 2008 (Stein *et al*., 2009; WHO, 2011). Thus it is clear that mental health care occurs in contexts that uniquely shape patients' experiences of care provision (Kittay, Jennings & Wasunna, 2005). Yet little is known about the logistical barriers to providing mental health services in Uganda. The present study addresses this knowledge and research gap by examining perspectives of patients

and caregivers regarding logistical barriers to providing mental health services in Uganda.

The conceptual and theoretical basis of the study

This study is conceptualised based on the health care systems model which posits that health care activities in any society are diverse but interconnected in a complex way (Kleinman, 1980). Helman (2007) has described such coexistence of diverse health care systems in local and cultural contexts as health care pluralism. As a collective entity, a health care system comprises elements such as patterns of belief about causes of illness, norms governing choice, evaluation of treatment, socially legitimated statuses, roles, power relationships, interactional settings and institutions (Kleinman, 1980). Helman (2007) has described a health care system as a social response to disease in which illness and healing are core elements; these are culturally constructed experiences of the patients and activities of healers. Health care systems do shape the ways in which people label and treat illness in terms of the prevailing cultural rules or norms of their contexts. People's beliefs and behaviour with regard to instrumental and symbolic activities where illness is concerned are influenced by contextual factors, such as the available social institutions, e.g. hospitals; social roles, e.g. the sick role and the healing role; and interaction settings, e.g. a traditional healer's shrine (Kleinman, 1980).

Kleinman initially developed the health care systems model based on the theory of the social construction of reality (by Peter L. Berger & Thomas Luckmann in 1967). However, the theory of the social construction of reality has been refined into related theoretical frameworks such as social constructivism (Teater, 2010). Social constructivism posits that there is a dialectical relationship between people and their realities; that is, people create reality, which in turn influences people's experiences of their created reality (Teater, 2010). Social institutions such as hospitals are thus a product of human creative work; subsequently, people experience hospitals differently, for example, as patients and as doctors. Additionally, social constructivism recognises that people's reality is influenced by historical, social and cultural contexts. That is, reality evolves from people's social interactions within historical, social and cultural contexts (Fabrega, 1996). In particular, social and cultural contexts influence values and beliefs, which in turn influence individuals' experiences, for example, of illness, and interpretations of such experiences (Helman, 2007).

Furthermore, social constructivism suggests that objective facts do not exist outside of the subjective meanings people attach to the perceived reality (Teater, 2010). Moreover, people create ideas, such as patient or medication, as they are subjectively experienced, socially defined and internalised by means of socialisation. Such subjective experiences are subsequently perceived as the truth though the process known as externalisation (Hardcastle, Powers & Wenocur, 2004). Externalisation is the process by which people talk with each other about their experiences, validate their understandings of their experiences and develop habitual behaviours in order to realise their social goals (Hardcastle *et al*., 2004). Language is the means by which individuals express and explain their own constructed realities; it also facilitates people's attempts to understand

the realities of others (Teater, 2010). Because individuals construct their own realities, there is no objective reality or one truth (Hardcastle *et al*., 2004). This idea suggests that the views among the patients and their care providers regarding mental health services, in the context of this study, are equally valid in their unique contexts.

METHOD

Research design

A descriptive research design with a qualitative approach was adopted as it allows the use of flexible methods, such as in-depth interviews that are effective in studying people's lived experiences of mental illness and care (Holliday, 2010) and also facilitates the learning from an "emic perspective" (Babbie, 2010). According to Draguns and Tanaka-Matsumi (2003:757), an emic point of view "underscores notions and labels derived from the experiences within a culture". Because of the interest in describing how mental health care was understood in Uganda, the present authors used multiple sources of evidence to enable convergence of the data in a triangulated manner (Henning, Van Rensburg & Smit, 2009).

Study sites and contexts

The study was conducted among patients and psychiatric health workers from the Psychiatric Unit at a large public hospital and the families, religious healers and traditional healers of the patients involved in the study in Western Uganda. We chose to conduct the study among outpatients rather than inpatients, as the latter were often in a more dependent relationship with their caregivers and were less likely to perform capably in the interview process than the former. For each outpatient interviewed, one family-based carer was enrolled into the study. As the institution was a public hospital funded by the Ugandan Ministry of Health, the majority of its service users received free general health care. The selection of the large public hospital and the Greater Mbarara region for this study was, to a great extent, influenced by the fact that one of the authors is fluent in the Rukiga-Runyankole language, commonly spoken in Western Uganda, and familiar with the local culture of the region.

Participants

The primary participants involved in the study comprised patients and relevant others involved in the care of patients, namely family members, psychiatric health workers, religious healers and traditional healers. We adopted purposive and snowball sampling techniques to recruit participants into this study (Babbie, 2010) and enrolled the care providers successively, based on the initial insights, information and consent given by the patients.

ENROLMENT PROCEDURES FOR PARTICIPANTS

We enrolled and interviewed a relatively small number of participants as follows: (a) seven patients, (b) seven families, (c) seven psychiatric health workers, (d) three religious healers, and (e) three traditional healers. Sampling was conducted to saturation (Babbie & Mouton, 2001).

Patients

We adopted the following criteria for enrolling the patients into the study: (a) having a psychiatric diagnosis of either unipolar depression or bipolar disorder, (b) being an outpatient for at least six months, and (c) residing in the Greater Mbarara region. Enrolment of the patients into the study involved publicity of the envisaged study and screening of individuals who responded to the study advert. We publicised the study on notice boards at the Psychiatric Unit at the large public hospital to appeal to eligible and interested patients to communicate their willingness to participate. We also publicised the study at review sessions of patients at the Psychiatric Unit and at follow-up community visits.

Families

We adopted the following criteria in enrolling the families of the selected patients into this study: (a) status as a trusted confidant of the selected patient as indicated by the latter, and (b) close involvement in the care of the selected patient for at least 6 months. All the patients who were selected provided verbal consent to approach their families to request their participation in the study. Subsequently, a researcher made direct telephone calls to some families to introduce himself and to explain the study to them. Home visits were conducted for the families for whom initial contact via telephone was not possible.

Psychiatric health workers

To enrol the psychiatric health workers, we publicised the study on notice boards at the Psychiatric Unit and explained the study during the orientation week at the Psychiatric Unit. Interested persons were asked for their contact details so that they could be contacted at a later time.

Religious healers

Religious leaders were enrolled if they were identified by a patient as being involved in their care for at least six months and lived in the Greater Mbarara region. Patients provided study personnel with the names and physical addresses of those religious healers who had provided or were currently providing them with care.

Traditional healers

Traditional healers were enrolled on the basis of their involvement in the care of people with mental illnesses for at least 6 months. Study personnel also had knowledge of the traditional healers in the area from previous research projects.

After obtaining informed consent from each outpatient participating in the study, the research assistant verified their respective psychiatric diagnoses of mood disorders from hospital files and obtained confirmation from their respective attending psychiatrists that episodes of mood disorders were in remission and that the respective patients were psychiatrically stable.

Data collection instruments and methods

We developed interview guides, which were translated into Runyankole-Rukiga. We used individual in-depth interviews as the main method of data collection and

triangulated the sources of the data to enhance validity of the results (Henning *et al*., 2009; Yin, 2011). Interviews were conducted at each participant's home or office, depending on which was convenient.

Ethical clearance for the study was obtained from the Health Research Ethics Committee of the Faculty of Health Sciences at Stellenbosch University and from the Uganda National Council for Science and Technology**.** We also sought approval from the relevant authorities such as (a) the President's Office, Republic of Uganda, (b) the District Health Officer, Mbarara district, (c) the Executive Director of the large public hospital, and (d) heads of the families of each selected outpatient before enrolling individual participants into this study (Newman, 2004).

Data analysis

We analysed the data for patterns and themes using the thematic analysis method (Braun & Clarke, 2006). Thematic analysis is a flexible method of analysing qualitative data that may be carried out within both essentialist and constructionist paradigms. We conducted thematic analysis within the social constructivism perspective (Teater, 2010), thereby identifying latent themes across all the individual data sets. The data were coded to identify themes using a computer software program known as Atlasti 6.2 (Friese, 2012). The coding process involved open coding, in vivo coding, axial coding and selective coding (Saldana, 2009). Data analysis involved inductive, deductive and iterative processes (Bradley, Curry & Devers 2007). To accurately identify themes, the verbal transcripts were read for evidence suggesting processes, actions, assumptions and consequences (Straus & Corbin, 2008). We also identified metaphors, repetitions across the interviews and shifts in content that suggested relevant themes (Agar & Hobbs, 1985).

RESULTS AND DISCUSSION

We identified three main themes regarding logistical barriers to providing mental health services in Uganda. These themes are (a) inadequate staffing, (b) irregular medical supplies, and (c) the use of inferior medication to treat mental disorders.

Theme 1: Inadequate staffing at the large public hospital

All participants, except the religious and traditional healers, reported that inadequate staffing at the hospital was a major logistical barrier to providing mental health services to patients. For example, Bosi, a 30-year-old male nurse, stated:

> *"You sometimes find there are only two health workers in the ward who are supposed to treat patients, handle cleric work, make orders for the drugs, and to collect sundries from the stores. As a result, they cannot easily serve every patient. So, they use the attendants (families) to do some part of care and they report to the health workers when they need assistance."*

As the above quotation illustrates, Bosi associated role strain among psychiatric health workers with understaffing, because the workers were overburdened with multiple responsibilities. The inclusion of families as backup staff suggests that patients do not always receive care provided by trained health professionals. Because of the

understaffing, families are also unable to receive respite care when outpatients relapse and are readmitted.

Similarly, Mukiga, a 41-year-old male patient with unipolar depression, reported:

> *"At times, you reach at the hospital and you find the few available health workers are already tired and preoccupied with their problems; then they tell you to go back home. You have come to the hospital in pain and you have to go back home with your pain."*

This quotation indicates that Mukiga believed that psychiatric health workers neglected patients because of their work-related stress. As a result of this perceived neglect, patients were seen by this respondent as being powerless in their relationship with psychiatric care providers.

Furthermore, some participants reported understaffing to mean that the hospital depended unduly on part-time staff to care for outpatients. For example, Njuna, a 40-year-old female counsellor, stated:

> *"There is one counsellor for the whole hospital. I am here in the hospital, well but not here, because I am employed by Mbarara University of Science and Technology. When I come for one day and I see one, two or three patients, maybe I am done for the week. There is a big need but I cannot meet it and that is the bottom line. If I say let me be here full-time, I would end up getting a mental break down."*

This quotation suggests that Njuna believed that the mental health needs of both patients and psychiatric health workers remained unmet, as there are too many patients to be cared for by a single part-time counsellor. Attempting to meet the overwhelming psychological needs of patients and care providers on a full-time basis, according to Njuna, would also be a considerable burden, which was likely to lead to excessive psychological distress for a single counsellor.

Mugurusi, the 60-year-old father of Bwerere, a 20-year-old male patient with bipolar disorder, was similarly concerned about understaffing. He stated:

> *"It surprises me to see that up till today, the government has not yet trained and employed enough health workers to treat mental patients. If doctors were many, as the patients are consulting, some doctors would have time to greet the patients and their relatives, to counsel and educate us on mental illness. They would also appreciate our work and encourage us to continue caring for the patients."*

Importantly, Mugurusi indicated that the unmet mental health needs of patients and their families were apparent to government leaders and could easily be met by training and employing more psychiatric health workers. Mugurusi also indicated that inadequate staffing at the hospital constrained the provision of psychosocial care to patients and their families.

Researchers have in the past similarly found low levels of human resources to be a barrier to effective mental health care, especially in low- and middle-income countries. For example, Saxena, Thornicroft, Knapp and Whiteford (2007) reported a critical shortage of mental health professionals to be common in low- and middle-income countries, as there was only one psychiatrist in each of the following sub-Saharan African countries: (a) Chad (domestic population of 9 million), (b) Eretria (domestic population of 4 million) and (c) Liberia (domestic population of 2 million). Moreover, there was an average of 0.5 psychiatrists and 0.16 psychiatric nurses per 100,000 of each of the respective populations in low- and middle-income countries. The ratio of psychiatric health workers to the population, in contrast, was about 200 times higher in high-income countries (Saxena *et al*., 2007). Other researchers, such as Ovuga, Boardman, Wasserman (2007) and Saxena and Maulik, 2003) similarly reported human resources for mental health to be too low to meet the mental health care needs of populations in low- and middle-income countries. In fact, because a large number of clinicians are full-time researchers and administrators, the number of mental health professionals in clinical practice may be overestimated (WHO, 2007). Yet effective mental health care relies heavily on committed and skilled caregivers, more so than on advanced technology or equipment (Saxena *et al*., 2007). The paucity of human resources for mental health care in low- and middle-income countries may be due to factors such as the large-scale migration of mental health professionals to high-income countries (Farmer, 2010; Saxena *et al*., 2007), the low status of mental health professions, for example, psychiatry in comparison to medical specialisations such as surgery, better working conditions in the private sector than in the public sector, the former serving a small and more privileged middle class and the latter the majority of poorer people (Saraceno *et al*., 2007). There is also a lack of incentives to attract mental health professionals to work in rural areas, where the majority of needy people reside. A wide disparity in access to human resources for mental health is thus prevalent in many low- and middle-income countries. For example, Kigozi *et al*. (2010) reported that over 60% of mental health professionals in Uganda work in and around Kampala city.

The burden of care among psychiatric health workers, which participants in the current study indicated was the result of the increasing numbers of service users, has similarly been reported elsewhere. For example, Coetzee, Kagee and Vermeulen (2011) reported that in South Africa limited numbers of health workers for very large numbers of patients receiving antiretroviral treatment is a barrier to clinic attendance. Burnout among nurses and long waiting times for patients create conditions under which patients are reluctant to attend clinic appointments (Coetzee *et al*., 2011; Kagee & Delport, 2010). It is also associated with inadequate interaction between health workers and service users, thus preventing effective assessment and treatment of complex health conditions, such as, HIV/AIDS (Kagee, Remien, Berkman, Hoffman, Campos & Swartz, 2011). Kagee *et al*. (2011) also reported that in order to reduce the excessive burden among professional health workers, lay counsellors are recruited to provide pre- and post-test HIV counselling in South Africa. However, insufficient human and financial resources mean that lay counsellors do not receive adequate training, regular supervision

and support, and are thus unable to provide quality health services. Furthermore, Narayan, Chambers, Shah and Petesch (2000) reported that the lengthy time period involved in travelling to health units, receiving treatment, acquiring medicines and returning home was often a disincentive to care-seeking among poor people. According to Narayan *et al*. (2000), many patients also experienced hunger while awaiting treatment at health facilities, because they were unable to afford buying lunch away from home and were discriminated against by health workers, who were reported to favour patients with a higher social status than poorer patients.

Theme 2: Irregular medical supplies to the large public hospital

Participants reported that irregular medical supplies to the large public hospital was another major logistical barrier to providing mental health services to patients. For example, Nkore, a 48-year-old male patient with bipolar disorder, stated:

> *"I have been getting free medicines in hospital except in the last 2 months. Health workers have been advising us to buy our medicines in pharmacies in Mbarara town. Each tablet costs 200/= (R 0.625) and in one month I am supposed to buy medicines worth 15,000/= (R 47) but I always do not have the money to buy my dose."*

Similarly, Martha, a 34-year-old female religious healer who cares for a relative with a mental health condition, reported: "presently, when you go to hospital, the health workers tell you to go and buy the medicines in the pharmacy. At times you find that you do not have money to buy the prescribed medicines". These reports reveal that participants regarded out-of-pocket payments as a barrier to access and adherence to medical treatment, as many patients are poor. As they are unable to buy medication, adherence is poor. In addition, because they access care providers in an un-coordinated way, for example, at the hospital and pharmacies in Mbarara town, outpatients incur undue time and transport costs, which may in turn exacerbate poverty.

Psychiatric health workers reported being concerned about the lack of explanation by administrators regarding irregular medical supplies to the large public hospital. For example, Milly, a 35-year-old female psychiatrist, stated:

> *"There are no medications in the hospital, especially of recent, and even inpatients buy their own medications. There is no clear explanation from the hospital administrators as to why we don't have those medications … Of course our hands are tied because some patients actually cannot afford the medicines that we prescribe for them."*

From the above quotation, it appears that Milly perceived that a communication breakdown had occurred between psychiatric health workers and hospital administrators, precipitating uncertainty regarding provision of psychiatric care for patients. The lack of medical supplies is also seen to lead to ethical dilemmas for psychiatric health workers, who have to advise patients to buy their own medication, even though they could not afford to.

Participants also reported being concerned that patients often take partial medical treatments because of irregular medical supplies to the hospital. For example, Agaba, a 50-year-old male clinical officer, stated:

> *"Sometimes, for a patient who needs to take carbamazepine and haloperidol, we find there is only one drug and the other drug is not available in the hospital. When we ask patients to buy a dose for one month until their next date of review, they swallow one drug which we may have given to them because they cannot afford a full dose."*

Agaba regarded irregular medical supplies as contributing to non-adherence to medical treatment among patients leading to poor treatment outcomes, such as prolonged episodes of a mood disorder and severe side effects of medication.

The use of out-of-pocket payment as a financing method for psychiatric care has also been reported elsewhere (Saxena *et al*., 2007; WHO, 2007). Because people with mental illnesses are often poor (Lund *et al*., 2010; Perry, 1996), the out-of-pocket financing method can aggravate poverty and hinder adherence to psychiatric care. Besides, Saxena *et al*. (2007) reported essential psychotropic medication to be relatively expensive for service users in low- and middle-income countries. In particular, a year's supply of the cheapest antidepressant could cost patients in low- and middle-income countries twice as much as what patients in high-income countries would pay. Yet the gross national product for high-income countries is 12.5 times higher than for low- and middle-income countries (Saxena *et al*., 2007).

Similarly, the WHO (2007) reported the out-of-pocket payment method, widely used in low- and middle-income countries, to be an ineffective, inequitable and exploitative financing method for mental health care. The out-of-pocket payment method aggravates poverty and results in poor treatment outcomes, such as relapse, among service users (Narayan *et al*., 2000). In particular, the out-of-pocket payment method for mental health care often leads to disposal of livelihood assets and acquisition of debt among service users and their families (Van Damme, Van Leemput, Por, Harderman & Meessen, 2004). The use of the out-of-pocket payment method for mental health care may be due to the lack of appropriate infrastructure for more effective financing options, such as tax-based payments and health insurance (WHO, 2007). Okuonzi (2004), in contrast, attributed the introduction of the out-of-pocket payment method in the Ugandan health care system in the early 1990s mainly to conditions set by donors and vested business interests.

A few patients reported being understanding about psychiatric health workers who informed them about the unavailability of medication at the large public hospital. For example, Murungi, a 60-year-old female patient with unipolar disorder, stated:

> *"Health workers don't refuse to give us the medicines, but patients are too many to be sufficiently supplied with the medicines. In fact, I have never felt that the health workers deny me medicines. When I don't find medicines in the hospital, I get satisfied and I believe they are not there. If the medicines were available would the health workers eat them like food?"*

Murungi indicates that psychiatric health workers displayed honesty in caring for outpatients. She did not, for example, express suspicion that psychiatric health workers were embezzling medication for personal financial benefit.

Researchers have in the past similarly found the lack of essential medical supplies to be a critical barrier to effective mental health care in low- and middle-income countries. For example, Saxena *et al*. (2007) reported that about a quarter of low- and middle-income countries do not provide basic antidepressant medicines at primary health care facilities. In some low- and middle-income countries the supply of essential medicines either fails to cover all regions or is irregular. Yet effective pharmacological treatments for many disorders require uninterrupted use by service users over a long period of time (Saxena *et al*., 2007). Saraceno (2002) similarly reported that while approximately 85% of countries worldwide have essential drug lists, which they use as a basis for procurement of therapeutic medication in primary health care settings, about 20% do not include at least one anti-epileptic drug on their lists. The inability of many low- and middle-income countries to translate declarations and policies into services in the mental health sector has been reported elsewhere (Fistein, Holland, Clare, & Gunn, 2009; Stein *et al*., 2009).

Theme 3: The use of inferior medication to treat mental disorders

Participants, except traditional healers, reported the use of inferior medication to be a major logistical barrier to effective provision of mental health services to patients. Participants particularly indicated that patients experienced various challenges mainly associated with side effects of inferior medication. For example, Mutungi, a 35-year-old male patient with bipolar disorder, stated:

> *"There is a medicine that I took that made me feel very bad. Whenever I would take it, for example, I would see the world turning yellow and I would feel dizzy. I would realise that the medicine is very strong for my body."*

Side effects such as these often stem from the use of older generation psychotropic medication, such as imipramine, which can hinder adherence to medical treatment.

Similarly, Agaba, a 50-year-old male clinical officer, stated:

> *"If a patient is using imipramine or amitriptyline, he may suffer from postural hypotension, dry mouth, which is very common among our patients, skin rashes and sexual potency is reduced. Compared with some of the new drugs, such as fluoxetine, the medicines that we prescribe for the patients have severe side effects."*

The above quotation suggests that Agaba viewed the use of older psychotropic drugs as a leading cause of severe side effects of medication experienced by patients, leading to poor adherence. Agaba also expressed concern that patients were not able to access better (new) medication, which is not being dispensed at the hospital.

Some participants reported that they viewed side effects as major illnesses, second to the mood disorders among patients. For example, Frida, the 30-year-old daughter-in-law of Mukaira, a 64-year-old female patient with depression, stated:

> *"Her other problem is the medicines which she takes because they cause her to lose appetite and to become physically weak. You find she is very thirsty but does not like porridge and also she cannot drink milk because of high blood pressure."*

Similarly, Martha, a 37-year-old female religious healer, stated:

> *"Medicines which patients receive from the hospital make them physically weak. I mean, medicines are very strong, to the extent that they appear to cause another illness. Because of the side-effects of the medicines, patients tend to terminate medications whenever they feel better."*

These quotations indicate that participants believed that inferior medical treatment caused somatic complaints such as physical weakness among patients. Such somatic complaints also could be basic symptoms of mood disorders, such as depression. Patients were likely to terminate their respective medical treatments as a result of such beliefs.

Some participants reported that patients experienced dilemmas about adhering to medical treatment as they associated severe side effects with the use of inferior medication. For example, Nkore, the 48-year-old male patient with bipolar disorder, stated:

> *"I realise that if you insist on taking the medicines as prescribed by the doctors, you are going to be weak full-time and unable to work. When the medicines cause me to be physically weak, sometimes I explain to the health workers to reduce on the prescribed dose. Yet, I think that reducing on the dose triggers my frequent relapse."*

This quotation suggests that Nkole believed that determining an appropriate dose of medication for him to experience effective treatment was complicated by the inevitability of the severe side effects of such medication, on the one hand, and relapse, on the other hand. Nkole was forced to choose either adherence to a high dose of medication, and thus to suffer from occupational impairment, or a reduced dosage, and thus risk relapse. Because both of these choices were undesirable, Nkole experienced considerable psychological distress and discouragement in seeking psychiatric care.

Participants also reported that families often misunderstood the side effects of medication among patients, for example, seeing lethargy as laziness. Mariya, a 34-year-old female social worker, reported in this regard:

> *"Some patients take drugs and become very weak and if they were initially active in weeding the banana gardens and they can no longer do their part, the families will accuse them of many things. They say that 'because you are mentally ill you are lazy; you have so many excuses. You tell us that you can only eat food and you cannot do the rest of work'."*

The quotation above suggests that Mariya believed that the families blamed patients unduly for being lazy, because they are not aware of the side effects of medication. Such

accusations convey an attitude of blaming the victims of circumstances that are beyond the control of patients. Family neglect is likely to precipitate psychological distress and aggravate episodes of mood disorders among patients.

Other researchers have similarly found high doses of psychotropic medication to cause severe side effects among service users, such as hypotension, dry mouth, blurred vision, headaches, epileptic seizures, decreased libido, weight gain (Gadit, 2003; Roos, Joubert & Stein, 2001) and amenorrhea (Helman, 2007). Furthermore, while newer drugs find more favour among patients than older generation drugs, they are less accessible, particularly in low- and middle-income countries, because of their prohibitive costs (Saxena *et al*., 2007; WHO, 2001; WHO, 2009).

CONCLUSION

Participants regarded inadequate staffing, irregular medical supplies and the use of inferior medication as key logistical barriers to effective provision and utilisation of mental health services. Because of inadequate staffing, the hospital where the data were collected relied on patients' families and part-time health workers to provide mental health services. The hospital was also unable to effectively meet the psychosocial needs of care providers. In addition, paying out-of-pocket for mental health services, dispensing inadequate doses of medication, receiving partial medical treatment, and experiencing uncertainty regarding the availability of medical supplies were common among care providers and patients because of irregular medical supplies. Moreover, psychiatric health workers had a limited prescription kit comprised mainly of older psychotropic medication that is often associated with severe side effects. Implications of these logistical barriers to providing mental health services include job-related stress, burnout and dissatisfaction with care, poor treatment outcomes, non-adherence to medical treatment and aggravated poverty among patients and their care providers.

RECOMMENDATIONS

The data obtained in this study indicate the need for policy makers to raise the priority status of mental health on the public-health agenda so that it is allocated a fair share of resources necessary for effective patient care. Financial, human and material resources directed towards hospital- and community-based care should be commensurate with the large numbers of patients needing mental health care. Furthermore, mental health policy should encourage and support mobilisation of patients and families to advocate for improved mental health services. The collective voices of organised groups of patients and families may convince policy makers to allocate adequate resources and to formulate appropriate policies and legislation to safeguard the rights of people with mental illness.

Study limitations

Participants were selected from western Uganda and thus the study may have limited relevance to other regions in Uganda. However, to augment the quality of the results, we triangulated the sources of data by enrolling patients and their lay and professional care providers.

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